

May 7, 1985

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Dear Bob and Luc:

It was a real pleasure seeing you both in Atlanta during the international meeting on AIDS.

As we discussed, the time has come to decide on an appropriate name for the virus you both discovered independently, so that the epidemic and its related disorders can be properly defined and renamed. It seems only natural that you, more than any other investigator, should select a name for this virus. I am writing to express my opinion on this issue and to urge you to agree on a name for the virus as soon as possible.

The designation "Human T Lymphotropic Virus" (HTLV) appears to be most appropriate since 1) it has been used in the original publications by both of you; 2) it reflects the biologic characteristic of the virus; 3) it defines the type of target cell for this viral infection; and 4) no stigma is attached to the designation per se. I appreciate potential objections to the use of "III", and would like to suggest letters such as: R (Robert), L (Luc), G (Gallo), M (Montagnier), P (Paris and Pasteur), B (Bethesda), and E (epidemic).

In my opionion, abbreviations, such as AIDS, ARC, pre-AIDS, LA, et al., should not be used because of the following difficulties:

1) These abreviations are now closely associated with a stigmatized life-sytle (homosexuality and i.v. drug use) as

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well as high mortality. Clinicians frequently encounter patients who request the use of terms such as: "viral infection" instead of "AIDS", or "idiopathic hemangiosarcoma" instead of "Kaposi's sarcoma", on their medical records. The commonly used terms for the AIDS epidemic have serious psychosocial implications not only for the patients themselves but also for their family members. Many patients have lost their jobs and have been denied employment and/or health insurance because of such diagnosis. As a matter of fact, Haitians have been officially removed from the list of high risk groups in order to decrease the impact of such an association on Haiti.

- 2) The use of these terms with their associated stigma is likely to have devastating consequences on the family and social structure in the heterosexual population, which appears to be a slowly expanding risk group. It is very difficult for the physician to interpret such diagnoses to the family members of stricken patients in this group.
- 3) The terms AIDS, ARC, pre-AIDS, and LA singly or collectively do not cover the spectrum of this disease entity. Related disorders, such as dementia, thrombocytopenia, lymphomas and other malignancies are not included, nor are the pre-clinical stage and asymptomatic carriers accounted for by these terms.

On the other hand, such classification has resulted in inaccurate data collection and reporting in this epidemic. While it is speculated that one million persons are infected, only 10,000 AIDS cases have been reported to the Centers for Disease Control, a definite underestimation, which also leaves out the number of cases of ARC, pre-AIDS or LA, as well as those with the subclinical stage of the disease. Moreover, the impression has been created that the outcome of AIDS and its related infections is invariably fatal.

As we discussed in Atlanta, I will be very happy to host a short meeting for you in New York at which you can confer and choose the final name for the AIDS virus. Other key clinical and laboratory investigators could also be invited to define and rename the spectrum of this epidemic and its related disorders.

I have taken the liberty of sending a copy of this letter to Dr. Harold E. Varmus, Chairman, Retrovirus Study Group, and the members of this committee for their review and consideration for the retrovirus nomenclature.

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I look forward to hearing from you, with best personal wishes.

Sincerely yours,

Bijan Safai, M.D., DSc Associate Member Sloan-Kettering Institute Chief, Dermatology Service Memorial Hospital

BS/emh

cc: Drs. H. Varmus

J. Coffin

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